



ORIGINAL ARTICLE

Parkinson's disease patients' needs during the COVID-19 pandemic in a red zone: A framework analysis of open-ended survey questions

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Abstract

Background and purpose: During the first phase of the COVID-19 pandemic, a lockdown was imposed in Italy. The aim of this study was to investigate the perceptions, feelings and unmet needs of Parkinson's disease (PD) patients who experienced the 2-month lockdown in a "red zone" in the northern part of Italy during the COVID-19 outbreak.

Methods: The study had a descriptive design that used a cross-sectional online survey which included open-ended questions to elicit responses on the participant's feelings concerning their risk of contracting coronavirus, how their physical activity had changed, and their personal needs, dictated by their condition, which were not met in this pandemic period as compared to previous periods. Demographic data were analysed using descriptive frequencies, while the open-ended questions were analysed using thematic framework analysis.

Results: The study included 103 participants (63 men/40 women [61.17 vs. 38.83%]). Framework analysis led to the identification of four main themes: (i) fearing the risk of contracting coronavirus; (ii) reduction of physical activity; (iii) perception of the risk of not being able to access outpatient clinics or support services; and (iv) negative experiences of the important reduction in socialization. The perceptions of unmet needs appeared to be greater than the actual experience, particularly for the reduction in physical activity and the interruption of contacts with the neurologist and other specialists.

Conclusions: This study highlights how perceptions and actual experience shape the meaning of living with PD during the pandemic. Worth noting is the divergence between perceptions and real impact in some aspects of the COVID-19 outbreak.

KEYWORDS

COVID-19; needs, Parkinson's disease, qualitative analysis, qualitative research

INTRODUCTION

In early December 2019, the first pneumonia cases of unknown origin were identified in Wuhan, China. The pathogen has been identified as a novel enveloped RNA betacoronavirus2 named severe acute respiratory syndrome coronavirus 2 (SARS-CoV2), causative of the coronavirus disease 2019 (COVID-19).[1] In the following months, the COVID-19 outbreak took on pandemic proportions, affecting over 100 countries [2,3]. By the end of February 2020, Italy had become the center of the European outbreak, with two COVID-19 hotspots located in two small geographical areas of northern Italy located in Lombardy and the Veneto, followed rapidly by another hotspot in the Emilia Romagna region [4,5]. Due to the rapid spreading of the outbreak, on 8 March the Italian government decided to extend the extraordinary measures (quarantine, strict restrictions to personal mobility, closing of schools, shops and industrial activities) already in place in the original hotspots to all of Lombardy and the neighboring provinces (Emilia-Romagna, Veneto and Piedmont), the so-called "red zones", and subsequently to the whole country [6]. Indeed, Lombardy, Piedmont, Emilia-Romagna and Veneto were the regions most affected in Italy by COVID-19 during the first wave of the pandemic [7,8]. Thanks to the contagion decline during the second part of April, the Italian government ended the lockdown in the whole country on 4 May 2020.

The emerging literature has confirmed that the global outbreak has had important consequences in the management of Parkinson's disease (PD) patients [9–11]. Foremost, it required a drastic and flexible adaptation to new circumstances, a cognitive operation that depends on normal dopaminergic functioning that could be impaired in PD patients [10]. The pandemic also imposed a marked reduction in physical activities, which could have negatively influenced patients' motor and mental well-being [10]. Not least, it disrupted attendance of periodic check-up schedules with patients' neurologists, physical and speech therapists, and primary care providers, which could also have led to worsening the clinical conditions of many patients with PD. Globally, the compromised healthcare, the lockdown restrictions, and the overall stress during the COVID-19 pandemic could have severely affected PD patients [12]. Accordingly, to investigate the perceptions, feelings and unmet needs of PD patients who experienced a 2-month lockdown in the red zones during the COVID-19 outbreak, we promoted an online survey among PD patients and caregivers (CGs).

METHODS

We employed a descriptive design utilizing an online survey service (i.e., a Google form) to address the study's aim. PD patients or their CGs could access the survey.

Participants' recruitment

Participants were recruited from the main provincial hospitals in Reggio Emilia and Modena (Italy). The target population was invited to

complete the questionnaire via e-mail and via PD patients' local association newsletters and social networks. At the beginning of the survey, participants were provided with a written description of the study's aim and the contact details of the principal investigator (F.C.). Participation was voluntary and no material incentive was given to respondents.

Survey

The survey was planned in two different versions to be used either by the PD patients or by their CGs, so that if patients were unable to answer despite wanting to, CGs could respond instead. All the questions referred to the PD patients' condition and experience during the outbreak.

With regard to item selection, we chose the main topic areas from the emerging literature on the pandemic-related consequences for PD patients [9–11]. Items on demographics and clinical conditions were decided on the basis of our expertise. Each questionnaire comprised 22 items covering demographic characteristics (age, gender, region of provenance, education) and clinical condition (time since PD diagnosis, ongoing specific treatments, quarantine experience, fear of contracting COVID-19 infection via an open-ended question); neurologic service provision and therapeutic relationship with the neurologist (four closed items and four open-ended questions); physical activities during the pandemic (two closed items and an open-ended question); and perceptions of healthcare-related needs (two open-ended questions). A provisional version of the survey was piloted by five conveniently sampled PD patients who gave feedback on its readability and comprehensibility. Some questions were modified accordingly. The survey was available online (25 May–10 June 2020) and took 10–15 min to complete.

The core open-ended questions on which the present paper focuses were:

- How do you feel about the possibility of contracting coronavirus?
- What are the needs related to PD which risk not being satisfied in this pandemic period? (This question was further probed with the following: Among the needs dictated by your condition, which have not been met in this pandemic period compared to the previous periods?)
- Can you describe how your physical activity has changed?

Data analysis

Demographic data and information from closed-ended questions were analyzed using descriptive statistics, while the open-ended questions were analyzed using framework analysis. This is an analytic approach that was considered appropriate for observing themes emerging from short and numerous answers by a multidisciplinary research team [13]. In addition, the framework method encourages themes to emerge inductively [14].

The first two authors analyzed the content that emerged from the open-ended questions provided by the first 30 respondents in order to identify themes and subthemes. The answers were subsequently

aggregated into more recurring and salient themes. Subsequently, these thematic categories shaped the initial framework, which was discussed with a third author (L.G.). The redefinition of the framework was discussed among all the authors. The shared framework was then applied to the remaining answers by the first two authors. Themes were also quantified using frequency counts, and patterns among the different types of respondents were highlighted. The majority of the participants responded to all the questions of the survey, while a minority of participants did not respond to all the survey's open-ended questions. For each question, the percentages of the different responses were calculated on the basis of the number of respondents and not on the total number of participants.

Ethical considerations

The Ethics Committee of Reggio Emilia was approached, and we were advised that, according to Italian law, formal ethical approval

was not necessary as respondents' identity and data were anonymous. The study protocol was in accordance with the 1964 Helsinki declaration.

RESULTS

Table 1 summarizes the study population characteristics. A total of 111 participants completed the survey; we excluded eight patients because they came from a region not included in the red zones (Lazio: $n = 5$; Toscana: $n = 1$; Puglia: $n = 1$; Sicily: $n = 1$). The remaining 103 participants were included in the analysis (patients: 67/103; CGs: 36/103; men 63/103 [61.17%]; women: 40/103 [38.83%]). The majority of participants were in the age range of 61–70 years (54/103 [52.42%]), came from the Emilia Romagna region (96/103; 93.20%) and reported a PD duration of ≥ 5 years (64/103 [62.13%]). Twenty-one participants (20.38%) were being treated with deep brain stimulation. Only four patients (3.88%) had been in quarantine

TABLE 1 Participant characteristics

Variable	Patients		CGs		Total	
	n/N	%	n/N	%	n/N	%
Age						
41–50 years	3/67	4.48	0/36	0.00	3/103	2.91
51–60 years	15/67	22.39	1/36	2.78	16/103	15.53
61–70 years	39/67	58.21	15/36	41.66	54/103	52.42
71–80 years	10/67	14.92	12/36	33.33	22/103	21.35
>80 years	0/67	0.00	8/36	22.22	8/103	7.76
Gender						
Female	26/67	38.80	14/36	38.89	40/103	38.83
Male	41/67	61.20	22/36	61.11	63/103	61.17
Italian region of provenance						
Emilia Romagna	61/67	91.03	35/36	97.22	96/103	93.20
Lombardy	3/67	4.48	0/36	0.00	3/103	2.91
Piedmont	1/67	1.50	0/36	0.00	1/103	0.97
Veneto	2/67	2.99	1/36	2.78	3/103	2.91
PD duration						
<2 years	6/67	8.95	5/36	13.88	11/103	10.67
2–5 years	17/67	25.38	11/36	30.56	28/103	27.18
>5 years	44/67	65.67	20/36	55.56	64/103	62.13
PD treatment						
No	2/67	2.99	1/36	2.78	3/103	2.92
Yes	65/67	97.01	35/36	97.22	100/103	97.08
Treatment type						
Pharmacologic treatment	48/67	73.84	31/36	88.57	79/103	79
Deep brain stimulation	17/67	26.16	4/36	11.43	21/103	21
Subjected to quarantine						
No	64/67	95.52	35/36	97.22	99/103	96.12
Yes	3/67	4.48	1/36	2.78	4/103	3.88

Abbreviations: CG, caregiver; PD, Parkinson's disease.

after COVID-19 infection. A detailed description of participants' characteristics and responses to closed items is reported in Table S1. The whole study sample answered the questions on needs. With regard to the open-ended question on fear of contracting coronavirus, the dropout rate was 11.66% (nine patients and three CGs), which decreased to 4.49% (two patients and two CGs) regarding the open-ended question addressing physical activity (Table 2).

The qualitative analysis yielded four main themes: feeling fear and anger; change in physical activity; interruption of contacts with the neurologist and other specialists; and missing socialization opportunities.

Feeling fear and anger

In our analysis, 91 participants (88.34%) expressed several feelings about the possibility of contracting coronavirus. Thirty-nine participants (including both patients and CGs) did not report on specific worries, since they felt secure in their home. Nonetheless, negative feelings were also reported from the other participants. In a shared situation of uncertainty, many respondents ($n =$

Quite worried because I also have an autoimmune disease so maybe it can complicate the eventual situation.
(Patient 6)

A lot of fear and discomfort thinking that if I had contracted the virus, I would not have had adequate healthcare.
(Patient 37)

I am afraid because I think I cannot survive.
(Patient 39)

30 [32.96%]) felt fear. While some patients said that they were afraid of dying, others reported they feared infecting loved ones and not having proper care if COVID-19-positive, to the point that some even skipped scheduled follow-up visits at the hospital. For some patients, having PD was perceived as a predisposing factor to severe illness from the virus. One patient had an autoimmune disease, and this made him feel worried.

In addition, patients were convinced that PD and related treatments could intensify their condition in the case of becoming infected. Twelve patients reported being concerned that the virus could worsen their PD condition.

My fear is that Parkinson's will get complicated.
(Patient 17)

Certainly fearful, as dealing with both Parkinson's and coronavirus together can obviously worsen my health.
(Patient 29)

Four PD patients described their emotional state concerning the possibility of contracting the virus as one of feeling defenceless and angry. Six CGs answered that their loved ones could not be completely aware of the pandemic due to cognitive decline, so no specific feelings were conveyed.

Change in physical activity

The theme of change in physical activity emerged from different questions. When we asked about the perception of needs at risk of being left unmet, the majority of our participants ($n =$

I needed to go out, to be outdoors, to feel free.
(Patient 63)

The possibility of going out and moving, which helps him a lot in the disease, in fact, he is actually getting worse in his movements....
(CG 35)

57; 55.03%) reported the absence of physical activity. To the questions concerning the participants' direct experience, only 34 patients answered that they perceived this as an unmet necessity. In general, the prohibition of outdoor exercise was considered a vital shortcoming for participants, namely, as a possible cause of symptoms worsening.

Since Italian lockdown measures required people to remain at home, the majority of participants ($n =$

I felt the interruption of all physical activities, such as swimming.
(Patient 48)

It is impossible to do physical activity at home.
(CG 6)

85; 82.52%) described changes in physical activity. Thirty-six participants (42.35%) felt they were forced to stop any physical activities, whereas 32 (37.65%) reported they adjusted to home exercise, and 17 participants (20%) considered activity insufficient.

Compared to the period before the pandemic, the absence of physical activity was experienced as critical for the maintenance of residual motor skills.

The motor activity carried out with family members is not as specific as the one performed with a physiotherapist.
(CG 1)

There was a lack of adapted gymnastics, speech therapy and cognitive stimulation....
(CG 2)

TABLE 2 Participant responses to the core open-ended questions

What are the needs related to PD, which risk not being satisfied in this pandemic period?						
	Patients (respondents: 67/67, 100%)		CGs (respondents: 36/36, 100%)		Total (respondents: 103/103, 100%)	
	N	%	N	%	N	%
Unmet needs during the pandemic period						
Physical activity	35/67	52.24	22/36	61.11	57/103	55.03
Access to outpatient visits	14/67	20.9	12/36	33.33	26/103	25.24
Socialization	7/67	10.45	3/36	8.33	10/103	9.71
Access to support services	3/67	4.48	2/36	5.56	5/103	4.85
Medication dosage control	2/67	2.99	1/36	2.78	3/103	2.91
No unmet needs	6/67	8.96	0/36	0.00	6/103	5.83
How do you feel about the possibility of contracting coronavirus?						
	Patients (respondents: 58/67, 86.56%)		CGs (respondents: 33/36, 91.67%)		Total (respondents: 91/103, 88.34%)	
	N	%	N	%	N	%
Perceptions related to Sars-CoV2 infection						
No particular worries	23/58	39.65	16/33	48.48	39/91	42.85
Fear and uncertainty about health status and age; afraid of dying; afraid of infecting others.	19/58	32.75	11/33	33.33	30/91	32.96
Concern about worsening of the clinical picture related to PD	12/58	20.68	0/33	0	12/91	13.18
Sense of impotence, anger	4/58	6.89	0/33	0	4/91	4.39
No awareness	0/58	0	6/33	18.18	6/91	6.59
Why did you get in touch with the neurologist during the outbreak? About what?						
	Patients (respondents: 28/28, 100.00%)		CGs (respondents: 9/9, 100.00%)		Total (respondents: 37/37, 100.00%)	
	N	%	N	%	N	%
Planned visit	19/28	67.85	3/9	33.30	22/37	59.46
Clinical worsening/treatment changes	7/28	25.00	6/9	66.70	13/37	35.14
Reassurances/questions about epidemiologic risk	2/28	7.15	0/9	0.00	2/37	5.40
How did you feel afterwards?						
	Patients (respondents: 28/28, 100.00%)		CGs (respondents: 8/9, 88.90%)		Total (respondents: 36/37, 97.30%)	
	N	%	N	%	N	%
Better	20/28	71.40	5/8	62.50	25/36	69.40
Same as before	8/28	28.60	3/8	37.50	11/36	30.60
Why didn't contact with the neurologist happen?						
	Patients (respondents: 39/39, 100.00%)		CGs (respondents: 25/27, 92.60%)		Total (respondents: 64/66, 97%)	
	N	%	N	%	N	%
No need	20/39	51.30	6/25	24.00	26/64	40.60
It was not possible to book	4/39	10.30	10/25	40.00	14/64	21.90
The visit has been cancelled	9/39	23.10	4/25	16.00	13/64	20.30
Fear to go to the hospital	5/39	12.80	5/25	20	10/64	15.60
The neurologist has died	1/39	2.60	0/25	0.00	1/64	1.60

(Continues)

TABLE 2 (Continued)

If you have needed of more contacts with the neurologist, what would the contact about?						
	Patients (respondents: 27/28, 96.40%)		CGs (respondents: 16/16, 100%)		Total (respondents: 43/44, 97.70%)	
	N	%	N	%	N	%
Disease control (symptoms worsening, therapies)	18/27	66.70	12/16	75	30/43	68.20
Reassurances/explanations	6/27	22.20	4/16	25	10/43	22.70
Need for human contacts	3/27	11.10	0/16	0.00	3/43	6.80
Can you describe how your physical activity has changed?						
	Patients (respondents: 56/58, 96.55%)		CGs (respondents: 29/31, 93.55%)		Total (respondents: 85/89 95.51%)	
	N	%	N	%	N	%
No physical activities	17/56	30.36	19	61.29	36/85	42.35
Home-only activities	22/56	39.29	10	32.26	32/85	37.65
Poor activity, no walking	17/56	30.36	0	0	17/85	20
Among the needs dictated by your condition, which have not been met in this pandemic period compared to previous periods?						
Unmet needs during the pandemic period	Patients (respondents: 67/67, 100%)		CGs (respondents: 36/36, 100%)		Total (respondents: 103/103, 100%)	
	N	%	N	%	N	%
Physical activity	22/67	32.83	12/36	33.33	34/103	33
Nothing	21/67	31.34	11/36	30.55	32/103	31.06
Socialization	16/67	23.88	9/36	25	25/103	24.27
Access to outpatient visits or support services	8/67	11.94	4/36	11.11	12/103	11.65

Abbreviations: CG, caregiver; PD, Parkinson's disease.

Interruption of contacts with the neurologist and other specialists

The perception of risk of not being able to access outpatient clinics or support services ($n = 34$ [25.24%]) was higher than the respondents' actual experience ($n = 12$ [11.65%]) during the pandemic.

The concern of not being able to attend checks, visits.
(CG 28)

The impossibility, given the coronavirus emergency period, of being able to be followed scrupulously as in normal periods.
(Patient 29)

Regular visits were frequently suspended during the lockdown: 44 participants (42.71%) admitted that they wished to have more contact with the neurologist during the outbreak. The majority of these ($n = 30$ [68%]) would have had a conversation about symptom control and therapy. Ten patients (22.70%) would have appreciated reassurances or additional explanations about COVID-19's possible impact on PD. Three respondents (6.80%) admitted they felt alone

and needed some human contact with their neurologist. Among the participants who had maintained contact with their neurologist, the majority ($n = 25$ [69.40%]) stressed that they felt better, reassured, and comforted.

Missing socialization's opportunities

For PD patients, the lockdown intensified the scarcity of social relationships. While only 10 patients (9.71%) identified the lack of socialization as an unmet need, 25 (24.27%) declared that they suffered from the inability to meet with relatives and friends or to participate in group activities. Both patients and their CGs reported the significant lack of socialization and emotional support during the outbreak.

Feeling a little more alone in front of the disease.
(Patient 1)

I suffered from a lack of human relationships with my family members.
(Patient 66)

DISCUSSION

In this paper, we provide qualitative evidence regarding the impact of the COVID-19 pandemic on the perceptions, feelings and actual unmet needs of Italian PD patients who experienced a 2-month lockdown in the red zones. One of the most recurrent issues in our cohort concerned the emotional sphere, which was highly affected during the lockdown. Participants reported that they felt alone, with fear and anger being the primary emotions emerging from the analysis. This is in line with a recent study that reported an increased incidence of anxiety in PD patients ($n = 137$) and CGs ($n = 95$) compared to the general population during the pandemic, with a strong correlation between severity of anxiety in PD patients and fear of contracting COVID-19 [15]. Anxiety and worries about the concomitant situation were similarly reported in 58.6% of patients from a cohort of 99 PD patients assessed through semi-structured telephone interviews [16]. Furthermore, it has been shown that PD patients experienced worse stress, depression and anxiety compared with controls during the COVID-19 pandemic [12]. These features were also correlated with mental health and prelockdown PD characteristics [12]. Moreover, it is interesting to note that, in a recent study that tried to ascertain the perceptions and implications of COVID-19 in 100 patients with PD and their CGs, the majority of participants (patients: 82%; CGs: 85%) did not attempt to explore interactions between COVID-19 and PD, as they felt that there was no association between them [17]. This differs from our cohort, among whom many patients felt worry about the possible interactions between COVID-19 and PD.

With regard to unmet needs from the perspective of PD patients in the time of COVID-19 during the lockdown, many participants reported that, compared to the previous periods, they perceived a lack of clinical assistance despite understanding the epidemiologic risk and the need to limit access to the hospital and outpatient clinics in the red zones. Many participants admitted they felt more vulnerable to the disease because they could not attend neurologic visits. This was particularly true for patients being treated with deep brain stimulation, for whom the above-mentioned theme may be of greater importance keeping in mind the dependence of these patients on a device which can only be checked or managed by the neurologist. However, this lack of assistance was not limited to assistance from the neurologist, but also extended to other specialists (general practitioners and physiotherapists). Again, this is consistent with another study investigating the impact of lockdown during the COVID-19 pandemic on quality of life in PD patients, which evidenced the PD patients' inability to receive doctors' advice or guidance regularly as the biggest self-reported problem, and this was also cited as a cause of impairment in quality of life in patients who had difficulty obtaining doctors' guidance and this impairment was even worse in those who changed their routine medication due to lockdown [18].

With regard to the type of contact with the neurologist during the lockdown, we obtained heterogenous results, which underlines the difficulty in reorganizing the care of PD patients during the pandemic. Indeed, the COVID-19 pandemic and the enforced lockdown

in many regions of the world has forced a substantial restructuring of the way in which care is delivered to patients with PD [19]. In this setting, the implementation of telemedicine to deliver urgent and ongoing healthcare has rapidly spread [10,20,21], even though the real impact of telemedicine on the doctor-patient relationship and patient satisfaction still needs to be assessed [19]. Regardless of the type of contact, it is interesting to note that the majority of our patients felt relieved after contact with the neurologist, emphasizing again the role of clinicians even in unusual settings such as telemedicine or telephone contacts.

Another aspect of unmet needs concerns the supply of medication. A study that enrolled 100 patients with PD and their CGs confirmed the inability to access healthcare and difficulty procuring medication as being among the main problems faced due to COVID-19 [22]. These findings underline again the need for better healthcare planning and implementation to cater to patients with chronic neurologic diseases such as PD, which may significantly worsen in the absence of appropriate expert advice from regular hospital visits [18,22]. Remarkably, from the analysis of our data, we note that the perception of the risk of not being able to access outpatient clinics or support services differed from the actual experience and the patients' unmet needs.

Reduction in physical activity has been reported as one of the main issues which negatively affected PD patients during the lockdown period. Indeed, most of the participants reported that they had drastically reduced their physical activity. However, again, our analysis evidences the difference in this context between perception and real experience. It has recently been reported that a reduction in physical activity represented one of the main risk factors for the significant worsening of general conditions during the lockdown in a cohort of 74 patients with PD [23]. Nevertheless, patients adapted their habits so as to continue practicing physical activity that was a main determinant of their well-being [23]. Moreover, another study, which included a total of 100 subjects, showed that during the COVID-19 pandemic the amount, duration and frequency of exercise were reduced: specifically, there was a decrease in the number of patients who took part in indoor solo exercise and an increase in those who did not exercise [24]. It is known that PD patients have difficulty in maintaining an exercise program independently over time, even if they are motivated and have adequate space available. This is based on the alterations in executive cognitive functions that impose the need to periodically re-learn motor patterns and to use external cues, a condition that can only be found in specific structures and under the guidance of physiotherapists experienced in PD [25].

Finally, our findings show the extent to which relationships with significant others were vital. Recently, a web survey was released including a large cohort of PD patients ($n = 1527$), with the aim of evaluating whether social isolation was associated with PD symptom severity and quality of life [26]. The authors found that social isolation was associated with greater patient-reported PD severity and lower quality of life. These results, together with our findings, emphasize the need to keep PD patients socially connected and prevent isolation in this time of social distancing [26].

Social interaction and motor activity therefore have a reciprocal potentiating effect. This has led to the promotion of unconventional motor activities such as dancing, Thai Chi and singing, which require and promote a closer relationship between people [27].

Globally, our results on the unmet needs of PD patients are in line with those of a recent survey in which people with PD not diagnosed with COVID-19 reported disrupted medical care (64%), exercise (21%), and social activities (57%), and worsened motor (43%) and non-motor (52%) symptoms [28]. Disruptions were more common for those living alone, those with lower incomes and those of non-White race [28]. The presence of an external stressor such as the COVID-19 pandemic leads to a worsening of PD symptoms by evoking psychologic distress as well as lifestyle changes [29]. Moreover, in a large multicentre study ($n = 832$), it has been reported that approximately half of patients reported dissatisfaction with their quality of life, with worsening of PD symptoms during home confinement [30]. These findings should be kept in mind, particularly at this time in which a large part of the world is facing the second wave of the COVID-19 outbreak.

To conclude, this study highlights how perceptions and actual experience shape what living with PD during the pandemic means. Worth noting is the divergence between perceptions and the real impact of COVID-19; the former seems to be worse than the reality. Nonetheless, patients and CGs act on the basis of the meaning phenomena have for them: when PD is lived as a condition facilitating severe infection, fear of not being assisted by healthcare providers or of inability to access services may arise. Additionally, in the situation of being forced to stop consultations, or of intermittent service provision, PD patients and their CGs risk being left unheard with regard to their needs and the information-seeking necessity. So, if on one hand the patients' perceived needs were amplified by fear and isolation, on the other hand, neurologists could be less able to respond to those needs, as they may be engaged in emergencies linked to the COVID-19 outbreak.

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CONFLICT OF INTEREST

F. Cavallieri received personal fees from Zambon outside the submitted work. F. Sireci, V. Fioravanti, G. Toschi, V. Rispoli, F. Antonelli, M. Costantini, L. Ghirotto and F. Valzania report no disclosures.

AUTHOR CONTRIBUTIONS

Francesco Cavallieri: conceptualization, data curation, methodology, writing -- original draft and final review Francesca Sireci: conceptualization, data curation, methodology, writing -- original draft Valentina Fioravanti: data curation, writing -- original draft Giulia Toschi: data curation, writing -- original draft Vittorio Rispoli: data curation and methodology, writing -- draft review Francesca Antonelli: data curation and methodology, writing -- draft review

Massimo Costantini: data curation and methodology, writing -- draft review Luca Ghirotto: conceptualization, data curation, methodology, writing -- original draft and final review Franco Valzania: conceptualization, data curation, methodology, writing -- original draft and final review.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

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